

**BIPOLAR DISORDER: PERSPECTIVES OF AFFECTED INDIVIDUALS
AND SIBLINGS**

by

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Bipolar disorder is a common and serious mood disorder that affects approximately 1% of the population. A major health concern, bipolar disorder can have profound effects on individuals, their family members and society. With heritability approaching 93% in some twin studies, the genetic etiology of bipolar disorder is under investigation. Molecular genetic studies have not revealed genes with large effect sizes. Based on the present information gained from twin, family and molecular genetic studies, a multifactorial inheritance pattern is suggested. As a result, genetic testing is not available for bipolar disorder. As genetic knowledge advances, however, it becomes increasingly important to imagine the role that genetic counseling may have for individuals with BPD and their family members. Thus, this study investigates the opinions and perceptions of individuals with bipolar disorder and/or their siblings on issues relevant to genetic counseling. A qualitative research design was employed. Tape-recorded phone interviews were conducted with twenty participants. Thematic analysis of the interview transcripts was utilized to characterize perceptions. Three main themes were identified: 1.) Individuals with bipolar disorder in their family appreciate the importance of a diagnosis and are concerned by perceived limitations with current methods of diagnosis. 2.) Bipolar disorder in the family can have profound effects on relationships, in both negative and positive ways. 3) Increased education and additional support may impact individuals with bipolar disorder and their families. Additionally, approximately 79% of individuals in this study expressed interest in pursuing genetic counseling

to discuss additional information and risks for family members. In addition to showing the interest in genetic counseling expressed by these individuals and their siblings, these findings also may provide a better understanding of the needs of this population. This work has public health relevance as it describes how a common disease can impact individuals and their families and how genetic counseling may provide them with an additional source of support. This study may become increasingly relevant as our understanding of the genetics of bipolar disorder grows.

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PREFACE

I am incredibly grateful to the individuals who participated in this project and shared their stories. They provided me with motivation and are what made this project so worthwhile for me. They inspire me.

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1.0 INTRODUCTION

Bipolar disorder (BPD) is a common and serious mood disorder that was first described more than 100 years ago. The diagnosis of BPD has since evolved from Emil Kraepelin's description of "manic depressive insanity" in 1907 (Kraepelin, 1907). BPD is characterized by severe mood symptoms, including episodes of mania or hypomania and depression.

A major public health concern, the lifetime prevalence of bipolar disorder is at least 1% (Merikangas et al., 2007). The World Health Organization reports bipolar disorder as the sixth cause of disability-adjusted life-years among all diseases (Murray et al., 1996). BPD can have profound effects on individuals, their family members and society, as this disorder can be disabling, resulting in personal and economic burden (Kessler et al., 2006). The direct costs of BPD involve not only the psychiatric component of the disorder, but also other medical care costs. In the United States, health care costs for an individual with BPD are estimated to be approximately two to four times higher than age and sex-matched general medical outpatients (Bryant-Comstock et al., 2002). Co-morbidities include obesity, insulin-dependent diabetes mellitus, hypertension and dyslipidemia (Alda et al., 2009). Furthermore, high rates of misdiagnosis, delayed diagnosis, lack of recognition and treatment of comorbid conditions often results in increased levels of chronic illness, disability, unemployment, marital dysfunction and mortality (Leboyer and Kupfer, 2010).

Severe disruptions in family dynamics can be seen, even when individuals are receiving treatment (Rosa et al., 2008). Consequently, a focus of research has involved identifying perceptions of individuals with bipolar disorder and their family members in attempts to use this information in clinical practice to improve their quality of life. One particular qualitative study completed by Holly Peay et al. in 2009 and published in the *American Journal of Medical Genetics* (Peay, Hooker, Kassem and Biesecker, 2009), sought to identify perceptions of these individuals and their needs related to genetic counseling. With permission, Perschke (2010) conducted a similar study using the same interview guide (Peay et al, 2009). Perschke noted that Peay and colleagues had conclusions that are relevant to genetic counseling practice and that there was value in conducting a similar study using a different population and different data analysis. Perschke concluded that direct questioning regarding interest in receiving genetic counseling would be a meaningful addition to Perschke's research.

Thus, the goal of this study was to further identify thoughts and opinions of individuals with BPD and their siblings regarding their thoughts on the impact of genetic information, the effect of BPD on their family, the value of education regarding BPD and their interest in pursuing genetic counseling. To fulfill this research goal, modifications were made to the interview guides used by Perschke (2010) including the addition of questions ascertaining interest in genetic counseling.

2.0 BACKGROUND AND SIGNIFICANCE

2.1 BIPOLAR DISORDER

Bipolar disorder (BPD) is a chronic psychiatric illness that often causes significant consequences for the quality of life of individuals, their family members and society (Angst and Sellaro, 2000). While BPD was first described by Emil Kraepelin over a hundred years ago (Kraepelin, 1907) as “manic depressive insanity,” the concept of affective disorders dates back even further. Homer uses the word mania to describe the mood fluctuation of some of his characters in his epic *The Iliad* (Lattimore R, 1961 translation). Kraepelin viewed all affective illness as one dominant diagnostic classification. In the 1950s, however, the proposal for both unipolar and bipolar illness was introduced. This was based on the presence or absence of manic episodes during the course of the condition. Individuals who experienced only depressive episodes were considered unipolar, whereas any individual with a manic episode was classified as bipolar (Angst and Sellaro, 2000). Presently, in DSM-IV TR (Association, 2000) the term “mood disorders” replaces “affective disorders” and unipolar has been replaced with the term “major depression” (Stefanis and Stefanis, 1999). BPD is a spectrum consisting of depression on one end and mania on the other.

Common features of depression in individuals with bipolar disorder include social withdrawal, lack of energy and motivation, sleep and eating disturbances and impaired

concentration and memory (Alda et al., 2009). It is not uncommon for depression that begins prior to puberty to ultimately manifest as bipolar disorder. This can lead to misdiagnosis of depression in children and improper treatment, as their manic episodes have not occurred prior to diagnosis (Kasper and Hirschfeld, 2005). To qualify as a manic episode, the symptoms must result in noticeable impairment on social or occupational functioning, psychosis, or hospitalization. The features of mania include elevated or irritable mood, inflated sense of self, decreased need for sleep, more talkative than usual, racing thoughts, distractibility, increased goal-directed activity and involvement in high-risk activities (DSM IV TR; American Psychiatric Association, 2000).

The two major categories of BPD include BPD I and BPD II. BPD I is associated with depression and mania, whereas BPD II is associated with depression and hypomania. Hypomania is a less severe form of mania involving an uncharacteristic change in function, but not marked impairment or psychosis (DSM IV TR). The lifetime prevalence of bipolar I disorder is 1% with an additional 1.1% prevalence of bipolar II disorder. Additionally, an even larger proportion of the population (2.4%) exhibits features of bipolar disorder but do not quite meet diagnostic criteria (Merikangas et al., 2007). The American Psychiatric Association is currently revising its DSM. Drafted changes are being put forth by the DSM-5 Mood Disorders Workgroup and can be found on the DSM-5 website (www.dsm5.org).

2.1.1 A comparison of BPD I and BPD II

A diagnosis of BPD I is made when a patient has experienced one or more manic episode (Association, 2000). A diagnosis of BPD II is made when a patient has disabling depression and at least one hypomanic episode (Association, 2000). Some studies suggest that individuals with

BPD II may develop less severe symptoms, but also exhibit a more chronic course with greater frequency of episodes (Vieta et al., 1997; Judd et al., 2003; Baek et al., 2010). Furthermore, disruptions in interpersonal relationships and adjustment, comorbidity (particularly anxiety disorders and eating disorders) and a higher risk of suicide are seen more frequently in individuals with BPD II than in BPD I in several comparative studies (Judd et al., 2003; Akiskal et al., 2006; Mantere et al., 2006). However, other studies have found similar rates of suicidal attempts and comorbid psychiatric illness for BPD I and BPD II (Vieta et al., 1997; Valtonen et al., 2005). Additionally, a higher frequency of social withdrawal and insomnia in individuals with BPD I has been observed (Coryell et al., 1995; Vieta et al., 1997). Thus, while there is a sufficient number of similarities between BPD I and BPD II, there may also be a number of differences between them.

2.2 LIMITATIONS OF CURRENT DIAGNOSTIC TOOLS

Individuals with BPD have a high risk of suicide, which has been reported to range from 25 to 50% (Jamison, 2000). The high prevalence, associated morbidity and suicidal risk of BPD reflect the necessity to diagnose correctly and timely. Currently, there is no diagnostic laboratory, or blood test, that can make a diagnosis of BPD. Clinicians must observe individuals for the signs of BPD and ask structured questions to elucidate mood and thought processes. Once a diagnosis is reached, treatment can be discussed. Potential consequences of under and misdiagnosis of BPD is well described (Akiskal and Benazzi, 2005; Leboyer and Kupfer, 2010; Wolkenstein et al., 2010; Zimmerman, 2010). Hypomanic symptoms, for example, are commonly missed. Consequently, BPD II is usually under diagnosed (Akiskal and Benazzi, 2005) and some

individuals diagnosed with major depressive disorder have, in fact, bipolar disorder (Zimmerman, 2010).

The majority of patients who are diagnosed with BPD experience a lag of at least 10 years between initial presentation and correct diagnosis (Zimmerman, 2010). Therapeutic strategies depend on an assigned diagnosis. Thus, a wrong diagnostic decision can be detrimental (Wolkenstein et al., 2010). Current research aims to improve diagnostic assessment (Zimmerman, 2010). Additionally, knowing the contribution of genetic risk factors may some day aid in making a diagnosis no longer completely reliant on clinical assessment. Or, perhaps this may permit the development of more specific and effective treatment options once a diagnosis is made (Barnett and Smoller, 2009).

2.3 GENETICS OF BIPOLAR DISORDER

A large number of studies have consistently reported that BPD aggregates in families. Numerous reviews have demonstrated that genetic factors are involved in the susceptibility to mood disorders, particularly bipolar disorder (Tsuang and Faraone, 1990; Merikangas and Swendsen, 1997; Moldin, 1997; Reus and Freimer, 1997; Sullivan et al., 2000). However, due to the complex genetic etiology of BPD and its multifactorial nature, the genetics of BPD remain unclear (Barnett and Smoller, 2009). Consequently, there is no genetic test in sight for the near future. Several study designs have been employed to assess the role genetic factors may play in BPD. These studies include family and twin studies, association and linkage studies, and genome-wide association studies. These are outlined in the following section.

2.3.1 Family studies

Studies examining families with BPD have revealed that the recurrence risk (the risks to relatives of developing the condition) for BPD in first-degree relatives of BPD ranges from approximately 9 to 17.5% (Smoller and Finn, 2003; Tsuang, 1980), which is approximately 10 times that of the general population lifetime risk. Smoller and Finn (2003) also reported that relatives of individuals with BPD are also at increased risk for major depressive disorder (MDD) as well. In fact, the risk to be affected with MDD is even greater than the risk for BPD for these individuals.

Family studies have also revealed that the transmission of BPD may vary according to the age of onset of BPD. This is a feature for some multifactorial conditions with an earlier age of onset conferring a greater risk for relatives. Early-onset BPD has been associated with greater risk to other family members in numerous studies (Pauls et al., 1992; Grigoroui-Serbanescu et al., 2001; Somanath et al., 2002). Prepubertal-onset BPD may even represent a particular form of BPD that may share a genetic etiology with disruptive behavior disorders, such as attention-deficit/hyperactivity disorder (Spencer et al., 2001). One controlled family study (Geller et al., 2006) found the risk for BPD to first-degree relatives of a prepubertal/early-adolescent onset individual with BPD to be as high as 46.5%. Additionally, this study found that individuals with ADHD were at an increased risk for BPD. Other features of BPD have also been shown to aggregate in families (Barnett and Smoller, 1999), including mood episode frequency, psychosis, lithium-responsiveness, suicidality, panic disorder and comorbid alcohol use disorder.

Family studies alone do not have the ability to prove that genes contribute to BPD, as both genes and the environment are shared between family members. Twin studies are used to help establish if the aggregation seen in families is primarily due to genetic factors. These

studies seek to identify if the concordance, or occurrence of BPD, is significantly greater among monozygotic twins or MZ (who are genetically identical) and dizygotic twins or DZ (who share approximately 50% of their genes). This comparison provides an estimate of the amount of heritability (proportion of a disorder due to genetic variation). Twin studies have shown that the concordance rate for BPD is much greater in MZ twins than in DZ twins, resulting in the heritability of BPD to be 79-93% (Barnett and Smoller, 2009). The concordance in MZ twins, however, is not 100%, which means BPD is probably caused by a combination of many genetic and environmental factors interacting together. These environmental influences may vary widely between individuals (Barnett and Smoller, 2009).

2.3.2 Molecular genetic studies of BPD

Presently, there are no single gene mutations known to cause BPD. Thus, at this current time it is believed that genetic factors are assumed to increase the risk for having BPD (Barnett and Smoller, 2009). As a result, genetic research for BPD involves searching for genes that are associated with risk for BPD.

2.3.2.1 Linkage

Linkage studies use genetic information from family members with and without the disorder in question. This method examines markers spread throughout these family members' genomes in attempts to identify regions of the genome that are passing through the family (appear to be coinherited) with the disorder (BPD). There have been many studies identifying regions of interest. However, there has been little consistency across these studies (Barnett and Smoller, 2009), and the exact genes responsible have not been identified. Linkage analysis has

proven successful for single gene conditions, or conditions caused by a small number of genes. Perhaps single genes carrying a great risk to develop BPD do exist, but are rare and specific to particular families (Barnett and Smoller, 2009). Regardless, it appears that the majority of BPD is explained by multiple genetic factors all contributing modest risk for disease. Therefore, association studies, reviewed next, are more suitable for this situation (Risch and Merikangas, 1996).

2.3.2.2 Association studies

Association studies investigate the relationship between a particular condition (BPD) and markers, or alleles, shared across individuals. These markers are based on evidence from linkage studies or from hypotheses based on the biology of the disorder, or neurobiology in the case of BPD. For example, many candidate genes for BPD are associated with neurotransmitter pathways central to BPD, such as the dopamine, 5-HT and glutamate systems (Cherlyn et al., 2010). Several genes in this pathway have been implicated in both schizophrenia and BPD, but replications are required to validate these results (Cherlyn et al., 2010). Additionally, specific genes have been associated with BPD such as schizophrenia 1 (*DISC1*), the dopamine transporter (*SLC6A3*), and several others (Baum et al., 2008; Fallin et al., 2009). However, none of these genes have been established as a susceptibility gene for BPD.

Genes involved in circadian rhythm are another area of interest for potential candidate genes. Disruption of circadian rhythm may contribute to BPD (Harvey, 2008). Modest evidence for this has been found in genes that control circadian rhythm, including *CSNK1E*, *BHLHB2* and *CLOCK* genes (Shi et al., 2008).

The selection of candidate genes is dependent on prior hypotheses of the biology of BPD and the validity of these hypotheses. Genome-wide association studies (GWAS), however, offer

a novel way to search for susceptibility genes without this need for an accurate hypothesis. GWAS uses DNA microarrays, or “gene chips,” that allow for the analysis of the entire genome. This gene chip is used to scan the genome for shared areas between individuals who have BPD. These shared areas, single nucleotide polymorphism (SNPs), are one of the hundreds to thousands of basepairs that comprises a gene, and provides for variation across individuals. Researchers use these tools to determine if a SNP occurs more frequently in individuals with BPD than in individuals who do not have BPD. The following genes were found to be statistically significant for an association with bipolar disorder from GWAS: *PALB2*, *DGKH*, *MYO5B*, *SKAP1*, *JAM3*, *SLC39A3*, *ANK3* and *CACNA1C* (Baum et al., 2008; Sklar et al., 2008; Ferreira et al., 2008). These genes carry diverse functions, including stabilizing chromosome structures and calcium and sodium channels (Baum et al., 2008; Ferreira et al., 2008). Results of GWA studies are inconclusive at this time, due to the inability to replicate results. This further suggests that there are many genes conferring small size effects while interacting with the environment (Barnett and Smoller, 2009).

As technology is vastly improving, methods such as large-scale genomic sequencing may provide a useful means to discover new disease associations (Barnett and Smoller, 2009). The ultimate goal, once confirmed and replicated associations are established, is to translate this into something beneficial to individuals with BPD. Perhaps identifying genetic risk factors will allow for therapeutic agents, such as tailored medications, to be designed specifically for individuals with particular genetic contributions (Craddock and Jones, 1999). Furthermore, as introduced earlier, identifying susceptibility genes may lead to the development of a diagnostic test, thus aiding in a diagnosis of BPD.

2.4 GENETIC TESTING FOR BIPOLAR DISORDER

When considering the type of genetic test that may one day be available, it is important to consider that the predictive ability of any potential test is limited when the effect size of a gene is small (Craddock and Sklar, 2009). Thus, the most likely result for a genetic test for BPD is one that would predict the probability of developing the condition. Therefore, the test would not provide a definitive result but instead the likelihood of developing bipolar disorder. This type of test exists currently for other conditions and thus is not an unreasonable expectation for the future. As a result, studies have explored the desire for genetic testing and perceptions of risk to develop bipolar disorder, which is discussed in the following section.

2.5 GENETIC COUNSELING FOR BIPOLAR DISORDER

As the potential for a genetic test or refined risk estimation improves, it becomes increasingly important to imagine the role that genetic counseling may have for individuals with BPD and their family members (Quaid et al., 2001). Furthermore, the availability of genetic testing is not a requirement for genetic counseling, as genetic counselors are trained to offer other resources and sources of support to clients (Austin and Honer 2007).

Although learning recurrence risks is often a primary interest for individuals pursuing genetic counseling, individuals seek genetic counseling for various reasons. A genetic counseling session for psychiatric conditions shares many commonalities with genetic counseling sessions for other complex disorders (Peay et al., 2008). During a psychiatric genetic counseling session for BPD, much of the session may be devoted to discussion of the causes behind BPD,

particularly the emphasis on both genetic and environmental components. A genetic counselor can incorporate what is already known about the disease, while also providing information on potential misconceptions (Austin and Honer 2007; Peay et al., 2008). A full discussion on the emotions surrounding issues of uncertainty regarding information provided by the genetic counselor, beliefs about BPD in terms of seriousness and chronicity of the illness, and emotions surrounding the potential environmental component can be addressed (Austin and Honer 2007). Austin and Honer (2007) argue that genetic counseling could provide a “supportive forum for patients and families to discuss the psychosocial impact of this information and its practical consequences” (pg. 254).

Exploration into the interest in genetic counseling for individuals with mood disorders and their family members has shown that the majority of study participants are interested in genetics education and counseling (Schulz et al., 1982; Quaid et al., 2001; DeLisi and Bertisch, 2006; Lyus, 2007). In particular, 75% of participants with BPD in one study stated that they would pursue genetic counseling if it were available (Quaid et al., 2001). Issues to consider when working with families with BPD are discussed in the following sections.

2.6 EFFECT OF BPD ON REPRODUCTIVE DECISIONS

Peay et al. (2009) addressed the effect of bipolar disorder on reproductive decision-making. Very few of the participants in this study who already had children reported that they considered the risk for mood disorders when they were making their reproductive plans. Importantly, almost all of these participants reported that they had not been concerned until they received their diagnosis of BPD, which was after childbearing was complete. Once receiving their diagnosis, several

parents expressed great concern regarding risk for their children. However, only one participant stated that she would not have had children had she known the risk. Most siblings also expressed that the risk for bipolar disorder was not a concern for them when having children (Peay et al., 2009).

Peay et al. additionally examined reproductive concerns for participants without children at the time of the study. These participants did express concern about the risks of psychiatric illness in future children. Furthermore, a small group (n=3) of individuals reported that they chose not to have children because of the perceived risk for mood disorders (Peay et al., 2009). A study from 1981, which consisted of 19 individuals with BPD and their spouses with 69% having children after the onset of BPD, all stated that the diagnosis did not affect their plans to have children (Targum et al., 1981). Additionally, this study found that if the risk was at least 15% to have a child with BPD, spouses were more likely than affected individuals to be deterred from having children, 74% (spouses) compared to 37% (individuals with BPD). Thus, even with potentially accurate risk information, individuals with BPD may be unlikely to alter their plans to have children. Furthermore, as this study indicates that spouses are more likely than affected individuals to consider not having children based on their spouse's diagnosis, there may be strong differences in reproductive decision-making between couples when one individual has BPD.

2.7 EFFECT OF PSYCHIATRIC ILLNESS ON THE FAMILY

The support of family members is essential for individuals living with a mental illness. Family members, however, can be heavily impacted by the disorder (Chang and Horrocks, 2006;

Jonsson et al., 2011; Peay et al., 2009; Veltman et al., 2002, Wynaden, 2007). Peay et al. (2009) reported that most individuals perceived BPD as significantly burdensome to the individuals affected with BPD and their family members. Often families experience great distress and strained relationships (Jonsson et al., 2011; van der Voort et al., 2009). Approximately 90% of family members report feelings of distress (Perlick et al., 2010). Isolation and forced self-sacrifice of social lives is seen more often in family members of individuals with bipolar disorder than other mental illnesses (Jonsson et al., 2011). Family members need support, education, and advice to cope with their family member's condition (Miklowitz, 2008).

While there are clear serious, negative effects on the family as a result of mental illness, empathy is a positive effect possibly gained through a family member living with BPD. Numerous research studies show that empathy appears to be increased in individuals with depression (Burns and Nolen-Hoeksema, 1992; Moran and Diamond, 2008). Additionally, gained empathy for siblings of individuals with developmental disabilities and psychiatric illness has also been described (Dauz et al., 2010; Dickens and Marsh, 1994; Dixon, 1997; Hodapp, et al. 2010; Flaton, 2006; Williams, 1997). A participant from Dauz et al. (2010) stated that their children (siblings) are more sensitive to other people with disabilities and more comfortable communicating as a result of their sibling living with a disability (Dauz et al., 2010). In a study of siblings of individuals with disabilities (Hodapp et al., 2010) 90% reported increased empathy as a result of growing up with their brother or sister. Additionally, the majority reported increased understanding, learning, awareness of injustices, compassion and awareness of family dynamics. Similarly, 86 participants in a survey of siblings of individuals with psychiatric illness reported increased empathy, tolerance and compassion. Additionally, their skills for coping with challenges were also enhanced (Dickens and Marsh, 1994).

Dixon (1997) details her own experience both as a sibling of an individual with severe mental illness and as a psychiatrist. She describes that her experience with her sibling had made her more empathic and has given her passion to provide direction and focus in her life. She recognizes that while she has grown and benefited from her painful experience, she would never choose this life for herself or her brother (Dixon, 1997).

2.8 STIGMA AND BIPOLAR DISORDER

The concept of perceived stigma for individuals with mental illness, including bipolar disorder, has been addressed in several studies (Hayward et al., 2002; Markowitz, 1998; Rosenfield et al., 1997). Smith *et al* (2006) identified that 68% of members of a support group for BPD identified BPD as highly stigmatizing. Stigma is likely to affect many aspects of an individual's life, including leading to withdrawal, isolation and a sense of burden (Austin and Honer, 2007). A recent study found that individuals with bipolar disorder present with lower rates of autonomy and fewer interpersonal relationships. They argue that as this may lead to embarrassment and discrimination, it contributes to high levels of perceived stigma (Vasquez et al., 2010). Stigma may lead to avoiding contact with others in fear of rejection (Angermeyer and Matschinger et al., 2003). Furthermore, stigma may affect the willingness for individuals to seek help or treatment (Sirey et al., 2001).

The advancement on research focusing on the genetics of bipolar disorder has gone hand in hand with recent studies examining the potential impact of discussing genetic etiology for BPD on stigma (Meiser et al., 2005; Dietrich et al., 2006). The participants in one study (Meiser et al., 2005) expressed that genetic attributions may decrease levels of stigma, as it would shift

the responsibility away from the “individual towards the role of heredity” (pg 116). Deitrich et al. (2006) showed, however, that providing genetic causal factors for mental disorders may lead to increased social distancing. Thus, these studies suggest that providing genetic information has the potential for various consequences regarding perceived stigma, both for the individual and for the family (Austin and Honer, 2007).

3.0 AIMS OF THE STUDY

This study aims to:

1. Identify the perceptions of genetic counseling in adults with bipolar disorder and/or their siblings.
2. Ascertain interest in pursuing genetic counseling for BPD.

4.0 METHODS AND PROCEDURES

4.1 PARTICIPANT RECRUITMENT

The recruitment and interviews of participants for this study was approved by the University of Pittsburgh Institutional Review Board (IRB) (REN10070213/PRO09070167). The letters of approval are found in Appendix A. Study participants were recruited from various sources. Flyers were posted on the University of Pittsburgh campus. Locations included outside of lecture halls and student counseling services and in Bellefield Hall, which holds an outpatient clinic that serves individuals with BPD and other psychiatric conditions. The researcher contacted the leader of the Pittsburgh chapter of the Bipolar and Depression Support Alliance (DBSA) and flyers were distributed through their support group meetings. Additionally, flyers were posted on a public online advertising site with the researcher's contact information, allowing for increased diversity in geographic location, including Pennsylvania, Illinois and Washington D.C. Lastly, snowball sampling technique was utilized to recruit participants.

Snowball recruitment is modeled after a public health concept "contact tracing" where an individual will name off other individuals who were associated with a specific event (Sadler et al., 2010). Similarly, snowball sampling uses one individual, the "source," who meets requirements for the study, to recruit similar participants. The goal is for the source to recruit participants who then recruit others starting a process that Wasserman et al. (2005) describe as a "snowball rolling down a hill." A meaningful advantage to snowball sampling is the cultural

acceptance among participants that it engenders (Sadler et al., 2010), as participants are referred to the study through an individual that they may trust. This may ultimately result in a more open discussion between the participant and the interviewer.

4.2 INTERVIEWS WITH RESEARCH PARTICIPANTS

The qualitative research design included conducting one-time interviews by telephone between September 2010 and February 2011. The author conducted all of the interviews. The interviews averaged 60 minutes and were audio taped and then transcribed. The interview included both open-ended semi structured questions, focusing on experiences and perceptions, and also a more structured portion, which employed clinical vignettes to capture participants' perceptions of a potential consultation with a genetics professional. The interview guides are found in Appendix B. The interview guides used in this study were adapted from a previous study published in the *American Journal of Medical Genetics* (Peay, Hooker, Kassem and Biesecker, 2009). This included adding additional questions, including demographic information and questions ascertaining participants' interest in attending a genetic counseling session.

There are many reasons that telephone interviewing rather than in person interviewing was chosen for this study. Reported advantages of telephone interviews include decreased cost and travel, and the ability to increase geographic diversity (Novick, 2007). Drawbacks include the need for a short interview duration and loss of visual or nonverbal cues. Despite potential drawbacks there are additional advantages to consider when working with individuals with bipolar disorder, or other psychiatric illness. These advantages include allowing participants to "remain on their own turf" (McCoyd and Kerson, 2006 p. 399), and permitting more privacy and

anonymity (Sweet, 2002). This may result in increased rapport and greater willingness to discuss personal stories. Thus, it was advantageous to conduct phone interviews for this particular study.

4.3 TRANSCRIPTION

The author transcribed nineteen of the telephone interviews verbatim from audiotapes using Microsoft Word by the author. A transcriptionist transcribed one interview. All personal identifiers were removed and participants were given pseudonyms. Transcripts preserved the language of the participants, as best as possible, including grammar and unfinished sentences. Some of the passages included in this report underwent minor revision, such as correcting grammar and removing pauses, to improve readability. This was done only when it was judged that the revision would not take away from the meaning of the passage but facilitate easier understanding for the reader.

4.4 THEMATIC ANALYSIS

Thematic analysis was the chosen method of analysis for this study. This involves, identifying, analyzing, reporting and describing themes and patterns in data (Braun and Clarke, 2006). The benefits of thematic analysis include its flexibility in analyzing data and its relatively understandable, obtainable use for a new qualitative researcher. As there is no clear agreement about how to conduct thematic analysis, it requires that users make active choices about the particular form of analysis chosen. Braun and Clarke (2006) describe a ‘recipe’ for researchers to

consider. This ‘recipe’ includes familiarizing oneself with the data, generating initial codes (detailed features of the data), searching for themes, reviewing themes, defining and naming themes and producing the report.

Braun and Clarke (2006) begin by discussing that the researcher must ‘familiarize’ themselves with the data. In this study the decision by the author to transcribe the majority of the interviews herself allowed for immediate immersion in the data. Next the entire data set was reread before the identification of codes was started.

Codes identify a feature, or concept, in the data that appears important or interesting to the researcher (Braun and Clarke, 2006). Codes must refer to the most basic part, or element, of the raw data in order to avoid missing the core meaning (Boyaltzis, 1998). The importance of detail in coding became clear and overcoming the tendency to want to over generalize a statement was important. Staying close to the data and using the language of the participants helped greatly to capture detailed codes. In general, answers to questions in this study had one central thought, although some participants provided various tangential thoughts to each answer. As a result, more than one code was applied to each answer in some instances.

To facilitate the search for themes, codes were organized in a three-column table. One column of the table contained the excerpt from the interview, the second column held the code and the third column contained the location of the excerpt for future reference.

Table 1. Coding table example

Excerpt	Code	Transcript Location
I think she struggles not to get angry with her husband, her coworkers. I've seen her get angry with strangers.	Struggles with anger	—

After all codes were entered into the table, they were rearranged into broader patterns, or themes. Braun and Clarke (2006) recommend the use of visual aids such as tables, organizing themes in piles, or maps. In this study, after organizing codes into columns, a map was created for each overarching theme to organize subthemes and codes. An example of this thematic map can be seen in Figure 2. This allowed for a visualization of what themes stood out as important to report and facilitated the ability to put codes in more than one theme if applicable. From these maps, three major themes were selected for this current paper. They will be described in the Results section.

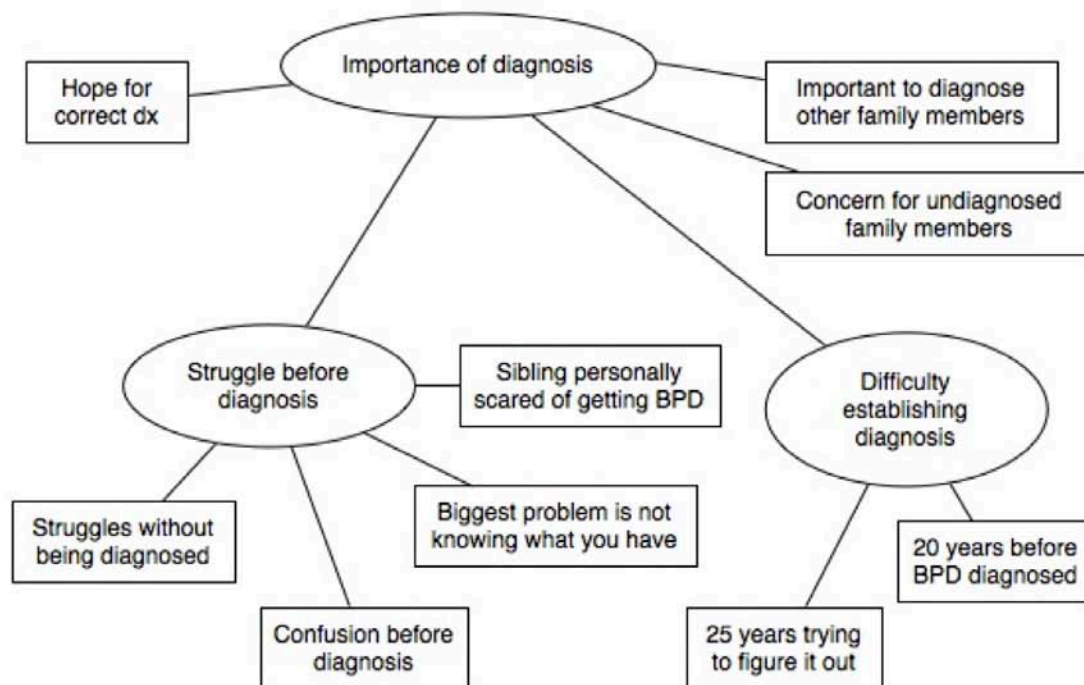


Figure 1: Thematic Map Example

5.0 RESULTS

5.1 CHARACTERIZATION OF THE SAMPLE

The analysis involved 20 participants. Thirteen of these participants had a diagnosis of bipolar disorder and 7 were siblings of individuals with bipolar disorder. Ages ranged from age 18 to age 70. Approximately 54% of individuals with bipolar disorder were on disability at the time of the study. Many individuals with bipolar disorder had children whereas most siblings did not have children. Most of the adults with bipolar disorder with children reported that they had children before receiving their diagnosis of bipolar disorder. The majority of participants resided in different cities across Pennsylvania. The remaining participants lived in Washington D.C and Illinois. The characteristics of the sample can be seen in Table 2. One participant answered that she was unsure if she would be interested in genetic counseling. Thus, this participant was not calculated in the percentage of individuals interested in genetic counseling.

Table 2. Characteristics of participants

Characteristic	Diagnosed participants (N=13)	Sibling participants (N=7)
Mean age in years (range)	52 (25-70)	32 (18-61)
Mean age at diagnosis in yrs (range)	41 (29-59)	26 (13-47)*
Race		
Caucasian	8 (61.54%)	7 (100%)
African-American	3 (23.08%)	-
Multiracial	1 (7.69%)	-
Unknown	1 (7.69%)	-
Sex		
Male	5 (38.46%)	4 (57.14%)
Female	8 (61.54%)	3 (42.86%)
# With children	10 (76.92%)	2 (28.57%)
# On disability	7 (53.85%)	-
* Age of affected sibling		

5.2 THEMES IDENTIFIED IN THE ANALYSIS

Analysis identified several themes capturing the perceptions of individuals with bipolar disorder and/or their siblings. The following section focuses on three main themes that were frequently mentioned throughout the interviews. Subthemes are discussed within each theme as participants' shared ideas overlap and connect within a major theme. Pseudonyms are provided for each individual.

5.2.1 Theme # 1: Importance of diagnosis

The first major theme identified in this study is the appreciation of an accurate and timely diagnosis of bipolar disorder by individuals with bipolar disorder and their families. The following discussion illustrates the issues surrounding obtaining a diagnosis and how it has affected these individuals.

5.2.1.1 Delay in diagnosis can lead to years of struggle

A common notion amongst adults affected with bipolar disorder in this study was the recognition that they lived many years without a diagnosis, or treatment, of bipolar disorder. The following remark was not uncommon.

As I look back now there were indications that the bipolar existed probably for twenty years at least, probably even longer.

The time this individual and others spent without an explanation for their symptoms was troublesome and confusing as they searched for an answer for their behaviors. The following participant, Abby, experienced symptoms of bipolar disorder for 25 years before she received a diagnosis.

It is very distressful because I went through 25 years of trying to figure out what is wrong with me. We just need to know. They really need to make this a priority like they do cancer or anything else.

Abby continued:

Really and truly one of the biggest problems is not knowing what you have or where to look for help.

Thus, these individuals felt that the current resources, or methods of diagnosis were not adequate and left them undiagnosed for years.

5.2.1.2 Informing relatives of signs and symptoms may alleviate struggle

Additional participants also recognized this struggle to receive a diagnosis and provided the following insight into ways to help expedite a diagnosis of bipolar disorder in family members.

It is awfully hard to live with. Anything possible that can be done, because so many people have struggled without being diagnosed and without knowing they are bipolar. It would make life so much easier if they [family members] knew what to look for.

This participant thought that encouraging family members to be informed of possible symptoms of bipolar disorder would help bring them to necessary medical attention earlier if needed. Another participant, Beth, was brought to the attention of healthcare professionals immediately after her symptoms manifested and received a diagnosis of bipolar disorder. She stated how she was “confused by what was going on.” She explained that her mother, who also has bipolar disorder, was able to identify signs in her daughter similar to her own and ask for help right away. Catherine, a sibling of an individual with bipolar disorder discussed the impact of acknowledging her family history:

It makes me more attune to learn the causes of the mental illnesses my family has been diagnosed with and to be attuned to symptoms of it, especially because I think a lot of people with mental illness tend to hide their symptoms from other people. I would make sure I am doing my best detective work, to find out if my kid was maybe depressed or having bipolar episodes and not telling me about it.

Thus, some individuals felt that informing family members of what to look for may help prevent the delay in diagnosis experienced by some of the participants.

5.2.1.3 Concern for undiagnosed family members

There was strong concern for family members who may be undiagnosed. Individuals who are affected themselves, mentioned the importance of involving family members in the

discussion of bipolar disorder, as there may be family members who are undiagnosed and unaware, as they were.

Catherine suffers from depression herself but is not diagnosed with bipolar disorder. Catherine wondered if there are undiagnosed members in her family. In the following passage she discussed how her sister's diagnosis of bipolar disorder causes her to question her own mental health.

There have been times where I have personally been scared that maybe that's [bipolar disorder] something that I have, because of the depression that I have. Because I get really low. And then I wouldn't say I ever get manic, or mania, where I can't control what I'm doing or are in the heights of the world, but I always wonder, well am I in a really, really good mood because something's wrong with me? Or am I just in a really, really good mood?

Although siblings' concern over their own mental health was not a common finding in this current study, it exemplifies the struggle individuals may face with the confusion over whether or not one has a diagnosis of bipolar disorder.

5.2.2 Theme # 2 Bipolar disorder affects relationships

Social relationships were impacted as a result of a family member's diagnosis for almost all of the participants in this study.

5.2.2.1 Social distancing

Many siblings expressed that the most difficult aspect for their family when dealing with their sibling's bipolar disorder was the self-isolation they saw enveloping their sibling, which impacted the entire family. One man, Adam, described it this way:

The worst thing for my family is probably again the social aspects of things. Maybe on Thanksgiving he'll be having a bad day, and so he just won't come to Thanksgiving, for example. That sort of thing where he may or may not be around and obviously family wants to spend time with him, but he may not feel like he's up to it.

Catherine had also noticed increasing distance from her sister since her sister's symptoms first appeared. Catherine described her sister as once care-free, but says now "everything is an issue" now that bipolar disorder has put a "dark, damp blanket" on her sister's life and has changed her. When she described her current relationship with her sister, she provided the following example:

I have noticed the past couple of years that she has been very distant, and kind of distracted. I'll be talking to her on the phone and she will just start screaming at her dog to like quit jumping on the sofa or something. It's like she doesn't hear anything I am saying."

Similarly, family members sometimes distanced themselves from the individual with bipolar disorder. Abby, who has a diagnosis of bipolar disorder, stated that she is very open with her family members and has even "sat down and explained the disorder to them." However, she disclosed that while she remains close with four of her five children, her oldest child does not speak with her. She stated that she "is the only one that just can't find it in her heart to forgive me. So we do not speak."

In addition to changes in interpersonal relationships between family members, social distancing was also seen in the limited number of friends that individuals with BPD have. One sibling, Benjamin, commented on what he feels is the most difficult aspect for his sibling with BPD to deal with:

I think not being able to have much of a social life. I mean he has a few friends that he trusts and they understand what's going on with him, but for the most part he doesn't really trust people as a result of friends being really weirded out by him in the past and kinda turning their backs.

David similarly comments that his sister has “a lot of social and emotional problems, such as making friends.”

Thus, relationships can be significantly altered, at times drastically, following a diagnosis of bipolar disorder.

5.2.2.2 A diagnosis of bipolar disorder results in distress for the family

The siblings of adults with bipolar disorder in this study mentioned that their sibling’s mental illness is stressful for both their affected sibling and other family members. Some participants described the stress felt as a result of concern over inadvertently upsetting their sibling. For example, Jessica stated:

We don’t know what will set her off. We could say something, or get in a small argument... and she may take it the wrong way. Or she may be in a bad mood or she may have had a bad day, so it’s definitely like a domino effect. It’s not like she is ever in a good mindset for really anything. She is always very angry and pent up and something’s all over the place.

Similar to Jessica, other siblings also discussed a constant struggle with anger noticed in their family member with BPD. They regarded the anger seen in their siblings as the most difficult aspect surrounding BPD for their family to deal with. Catherine described the anger she observes in her sister:

I think she struggles not to get angry with him [husband], not to get angry with her coworkers... I’ve seen her get angry at strangers. Sometimes around my mom she gets so uptight and angry. She spends a lot of her time, sometimes, in these rages.

Adam discussed a way he has adapted to his sibling’s episodes of anger:

There have been situations where I have helped calm him down, especially at family events. For example, if he starts to get real mad I know that he might want to walk around the block or something. That has helped sometimes.

Some individuals with bipolar disorder also recognized this stress that bipolar disorder brings to their families. For example, Beth commented:

It's an emotional roller coaster for them. They don't know day by day how I'm going to be. And I feel for them. I live with my husband. My family lives about an hour and a half away, but I live with my husband, and for him- it is very, very straining. It is very difficult to live with a person like myself and I acknowledge that. But at the same time, there's nothing I can do.

Beth understands the impact that bipolar disorder has had on her husband. Furthermore, Beth stated that she appreciates him, but also mentioned that she understands her own limitations. Another participant stated that his family lives with his diagnosis of bipolar disorder and understands it. He and Beth were able to work with their family, despite hardships, to get through the difficulties of having bipolar disorder. Conversely, another participant described that she has been unable to hold a steady relationship as a result of bipolar disorder. Additionally, she understands it is very trying for her family as well.

He [boyfriend] couldn't handle it. It just takes such a toll on family. You know what I mean? My aunt will start crying and then my dad will call and he will start crying.

Thus, bipolar disorder was identified as a recognized source of stress for the families in this study by both those with bipolar disorder themselves and their siblings.

5.2.2.3 Feeling a special connection to other family members

Some siblings perceived a shared connection between their sibling and other family members with bipolar disorder or another mental illness.

Catherine, who was earlier introduced and has a diagnosis of depression, described this connection she shares with her siblings, who all have some type of mental illness:

It is sort of a connection that we all have. I guess maybe the fact that she [sibling] has a mental illness, meaning she isn't going through this alone because we all have a mental illness of some sort. So maybe this link that we're all in this together.

Similarly, another sibling, David, stated, "she can relate to my dad, because he has it as well."

This special connection stemmed from a bond these family members shared with one another. They may have understood on a personal level what their family member was going through and appreciated that they were not alone as they struggled with mental illness. Thus, it was not uncommon in this current study for family members to find that they have a special relationship with family members who are also affected by mental illness.

5.2.2.4 Gained ability to relate to others outside of the family because of sibling's diagnosis

For some, the empathy experienced for individuals with mental illness seemed to extend beyond the individuals who are affected and on to their family members as well. David described that not only do his sister and father empathize with each other because of their shared diagnosis, but David also is able to "relate to anyone else who has it, or understand it."

Catherine raised the issue of whether or not we should try to eliminate a mental illness that results in a source of empathy and community. She continued:

My partner works in disability services and we think a lot about pride and community around mental illness and other disabilities and things like that. To totally eliminate something, I guess it would make somebody's life easier, but I don't know.

Thus, some individuals commented on how they have grown from their family members experiences and how their siblings' diagnosis have shaped them in a positive way.

5.2.3 Theme # 3 Education and additional support from a genetics professional may impact individuals with bipolar disorder and their families

The third major theme identified in this study is the interest many individuals expressed in educating family members about bipolar disorder and the importance of being aware of their family history. Participants also attested to the benefit that additional support could play in their lives.

5.2.3.1 Increased knowledge and education may benefit families with bipolar disorder

Many participants noted the complete shock they experienced when receiving their diagnosis of bipolar disorder. Consequently, they discussed the benefits that family education may have in preparing family members to identify signs and symptoms early and alleviate potential shock. The following illustrates the thoughts of one participant, Monica, about how family history information could benefit someone who may otherwise feel unprepared:

I think this [discussion of family history] would be useful, because if there's a chance she can get the disease, like develop bipolar like I did. If she knows she has a high possible percentage, or chance, she can do something to kind of...like I didn't know- I was shocked. Maybe she won't be so surprised and maybe when she finds out her high percentage she can do something to prepare herself or take care of herself better.

Furthermore, Benjamin commented that education and risk information is 'troubling' but also useful:

Yes, this information is useful and kind of troubling probably. I guess it can be useful to have that in mind and be aware of other people in the family and their actions and moods and knowing that yeah, something might be wrong, but at least we know what it is.

Similarly another sibling of an individual with bipolar disorder, Evan, commented:

...It could be good to be aware and I guess be ready because then you'll have an understanding if it does happen.

Thus, individuals in this study found that information about family history and risks would be helpful, especially in using this information to prepare for a diagnosis. The effect of this type of information on reproduction decisions is explored in the next section.

5.2.3.2 Reproductive decisions do not appear to be strongly affected by a diagnosis of bipolar disorder in the family

The seven siblings in this study all shared similar thoughts regarding how family history information would affect their choices to have children in the future. It was previously discussed that Evan believed family history information could be useful to have an understanding and allow for preparation; however, it would not change his views on having children in the future. He and the other participants did not feel that their siblings' diagnosis of bipolar disorder would or ever had impacted their thoughts on having children. One sibling stated:

I think it could be useful just to keep it in mind that it might happen. It's hard to say, from my opinion it wouldn't really change anything as far as it wouldn't be useful in that I would still want to have kids, but it might be good to keep in mind that it is a possibility.

Similarly, another sibling described that her 'plan' for the future would not be changed by her sibling's diagnosis of bipolar disorder.

I mean it makes me a little skeptical if I subject my children to any 'bad genes' that I may have. But I have a plan for the future and I think that won't be very much of a problem. I will look out for it and be aware, but I am hoping that once I have children maybe research will have gone a little bit further and maybe I can ease myself from that kind of thing.

Most of the individuals with bipolar disorder in this study were past reproductive age at the time of their diagnosis. These individuals had a difficult time determining whether or not this

would have impacted their decisions. Beth, who was at the time considering whether or not to have another child described her conflicted feelings when asked if her diagnosis of bipolar disorder had changed her plans to have children:

Yes absolutely. My first pregnancy with my daughter was a surprise, not planned. I mean it worked out, a happy surprise, but was not planned. I always thought about having children, but at the same time when I'm in a deep depression or mania, I'm like are you serious? But at the same time, like I said I have a husband who has a stable mental health history himself and for his family, so like I said at the same time even though I have the predisposition, doesn't mean my daughter is going to have it.

Earlier Beth had stated:

I fear that my daughter will have it but I believe that she won't because in my husband's family there isn't a strong predisposition for it. But, it is definitely a possibility nonetheless.

While the chance that a future child may have bipolar disorder in the family is something most individuals were aware of, in general it did not appear to strongly affect decisions regarding having children. Individuals who are affected with bipolar disorder themselves appeared more ambivalent on reproductive decision-making than the siblings in this current study.

5.2.3.3 Genetic counseling may impact stigma thought to be associated with bipolar disorder

The idea that individuals with bipolar disorder receive a label that carries stigma was often discussed in this study. This is exemplified in the following statement:

Even though it is more accepted now than it ever was before, there still is that stigma that people have, "oh you're a, you're mental." They still would look down on you, or wouldn't trust you to do certain things.

Similarly another individual, William, stated:

It's a very horrible thing to go through because people do not understand it and are quick to label people.

As a result of this perceived stigma, one participant voiced her concern about potential implications of genetic testing, including “putting someone in the mental health area of life,” by putting asymptomatic individuals in a mental health system. In addition, another participant, Catherine, debated whether or not providing genetic information will strengthen or weaken stigma.

I'm not sure that's necessarily a good thing, because I think this may further stigma against people. I mean it could in a positive way, it could further prevention and education and lesser stigma, but on the other hand it could further stigma. Because how would you feel if you knew you have a greater than 50% chance that your child is bipolar, and you know the struggle that people with bipolar go through, you know that some of them end up taking their own lives. I don't know that that is necessarily good information. I think living your life and dealing with things as they come is better, but I think it depends on the person, whether they want to know or not and deal with things as they come.

Catherine additionally commented that perhaps stigma may be lessened by genetics if the following is carried out:

I think in with genetic testing, part of the work has to be advocating and trying to eliminate the stigma of mental illness. To give people in these communities some hope and some pride that they can live a successful life with mental illness.

Thus, the idea that bipolar disorder carries a label, or stigma was heavily on the minds of some of these participants. Interestingly, a small number of participants commented on the compassion they felt from close friends and did not mention stigma, or fear of discussing their diagnosis, as an issue for them. In fact, when asked if she was treated differently because of her diagnosis of bipolar disorder, Beth stated:

I would say in a positive way because they know I'm sensitive towards certain things. They are aware of that and handle situations in a certain way to make me feel better. I am very open with it [bipolar disorder].

Similarly another participant commented:

People who are aware of my diagnosis do not treat me any differently. If anything, they are sympathetic, so maybe even a little better. I think I am more inclined to want to share with people as a result of knowing that people do care.

Thus, while stigma was a real issue for many participants, it was not a concern for everyone. Some individuals have received compassion and understanding from those around them who learn of their diagnosis.

5.3 DESIRE FOR ADDITIONAL SUPPORT

Approximately 79% of individuals (n=19) in this study expressed interest in attending a genetic counseling session. These individuals discussed that they were interested in education, additional support from a genetics professional and in learning about risks for themselves and their family members. The individuals who were not interested (n=4) noted that they and sometimes their families were involved in a great amount of other types of counseling and did not feel they could add anything else to their schedules. However, the majority felt that any additional professional support would be very welcomed. One individual commented:

I think any information would be useful to gain more knowledge and awareness to be able to even converse with other people and share information with other people. I don't think there's any such thing as not being useful when it comes to getting information from a professional [genetic counselor] like that.

6.0 DISCUSSION

This study is one of the few identifying perceptions and opinions of individuals with bipolar disorder and/or their siblings relevant to genetic counseling. The results identified several themes that were categorized into three main themes. These themes revealed the following: firstly, many individuals with BPD were concerned about the current methods of diagnosis. Secondly, siblings and individuals with BPD often saw major changes in their own lives and the lives of other family members. While this often came with great hardship for the family, such as social distancing and episodes of anger, positive effects including a greater sense of understanding and empathy were also sometimes noted. Lastly, individuals commented on the effect that increased education, including genetic counseling, might have on their families. They addressed issues such as the effect of increased knowledge of recognizing signs of BPD early, reproductive choices and stigma.

Furthermore, this study identified that the majority of individuals would be interested in genetic counseling if it were available to them.

6.1 STUDY FINDINGS IN THE CONTEXT OF PREVIOUS WORK

6.1.1 Theme # 1 Importance of diagnosis

As outlined in the background and significance section, there is no diagnostic laboratory, or blood test, that can make a diagnosis of BPD. Thus, a diagnosis relies exclusively on clinical findings that may be subtle and missed (Akiskal and Benazi, 2005). Additionally, the majority of patients experience a delay of at least 10 years before a correct diagnosis is made (Zimmerman, 2010). Thus, it was not surprising that several participants in this study expressed their distress over a delay in diagnosis at times over twenty years. The feeling of not knowing where to go for help, while struggling without a diagnosis, was concerning for these individuals. The desire to have a correct diagnosis to alleviate potential burden has previously been reported (Peay et al., 2009). Participants offered insight into how they thought this could be avoided in the future. This included sharing with family members what signs they should watch for so that these family members could then seek appropriate resources. One participant with BPD expressed their appreciation for their mother, who is also diagnosed with BPD, who recognized signs early and sought assessment and treatment for her daughter immediately. Similarly, participants in the Peay et al. study perceived the primary benefits of the clinical vignettes as the ability to monitor at-risk individuals and as a result identify symptoms early (Peay et al., 2009).

When discussing problems related to misdiagnosis, one sibling spoke about her concern that while she was diagnosed with depression, perhaps she actually has BPD. She explained that not having a definitive answer on this matter was concerning and she sometimes questioned whether periods of happiness in her life might be signs of mania. Similarly, Peay et al. (2009) noted that many siblings in their study were also concerned about their own mental health.

As genetic counselors are trained to discuss signs, symptoms and resources, they are well suited to discuss the importance of recognizing signs of BPD early. Furthermore, this type of conversation could easily take place while taking a family history, a component of most genetic counseling sessions. While some individuals may be the first person diagnosed in their family, perhaps for other families with a diagnosis of BPD already in the family, genetic counselors can provide education that may help prevent the delay in diagnosis experienced by many participants. Additionally, perhaps genetic counseling will prevent the feelings of shock described by one participant, who felt that a discussion with a genetic counselor would perhaps allow an individual to prepare for the potential condition.

6.1.2 Theme #2 Bipolar disorder affects relationship

As mentioned earlier, several studies examine the effect of bipolar disorder on family members and relationships (Veltman et al., 2002; Chang and Horrocks, 2006; Wynaden, 2007; Peay et al., 2009; van der Voort et al., 2009; Perlick et al., 2010; Jonsson et al., 2011). In agreement with previous research (Peay et al., 2009), this study also found a diagnosis of BPD to be a cause of burden and distress for the family. The sources of strain for individuals and family members included, episodes of anger, increase in distancing between family members and less social relationships. Many siblings described a constant struggle with anger and some even have attempted to help their siblings deal with their anger at family events.

A few siblings in this study commented on the understanding, compassion and empathy they feel they have gained because of their experiences with their sibling. They discussed that not only do they see their siblings empathizing with others with BPD, but also that they themselves are now able to relate to others with compassion. To my knowledge, this has not been

found previously for siblings of individuals with BPD. However, numerous studies explore this concept for psychiatric illness in general or developmental disabilities, as described earlier (Dickens et al., 1994; Flaton, 2006; Dixon, 1997; Williams, 1997; Hodapp et al., 2010; Dautz et al., 2010;). The majority of these siblings reported increased understanding, learning, awareness of injustices, compassion and awareness of family dynamics, as a result of growing up with their brother or sister. As bipolar disorder can affect family dynamics and many siblings observe the difficulties their brothers or sisters have had maintaining relationships and other great hardships, it seems reasonable that siblings of individuals with BPD will also be affected in this way.

One participant in this current study grappled with the issue of eliminating mental illness when perhaps we should instead be providing resources for individuals with BPD. She voiced her concern over wanting to make someone's life easier, but not wanting to eliminate a source of empathy for some individuals. As described earlier, Dixon (1997) a psychiatrist and sibling of an individual with a severe mental illness, expresses that while she appreciates her gained compassion from her experiences she would never choose this life.

6.1.3 Theme # 3 Education and additional support from a genetics professional may impact individuals with bipolar disorder and their families

Many participants in the current study described that they would be interested in receiving information on potential risks for BPD in their family, however it would not likely affect their decisions about having children. Siblings discussed that while it would not greatly impact their decisions, they thought it would be useful information and would use it to know what to keep watch for. This was also observed by Peay et al. (2009), as most siblings also expressed that the risk for bipolar disorder was not a concern for them when having children.

Individuals with bipolar disorder, however, were less sure of how this information would affect their choice to have children. Importantly, most participants in this study were past reproductive age at the time of their diagnosis. Many tried to imagine how this information would affect them, but this was difficult for them to determine. Nonetheless, most participants appreciate the benefit of gaining as much information as possible from healthcare professionals. Similarly, a previous study (Quaid et al., 2001) states that anecdotal evidence suggests that there is great desire for more information on psychiatric conditions when making childbearing decisions. Some of the participants (adults with BPD and/or their siblings) from Peay et al. (2009) were of reproductive age. Most of these participants expressed concerns about the risk of psychiatric illness for their future children. A small group of affected individuals and siblings reported that they chose not have children because of perceived risk for mood disorders. One participant in this study explained this was because they did not want to “inflict whatever illness” they had on an “innocent child” (Peay et al., 2009).

The impact that genetic information and education regarding genetics and BPD may have on stigma is described in this study. One participant questioned whether this information will lessen stigma by furthering education on BPD in a positive way or if it will increase stigma instead. The first possibility is reminiscent of a comment by Austin and Honer (2007) who remarked that educating affected families and enabling them to share their new knowledge with other relatives and friends may reduce stigma. A few participants in this study voiced concerns over “putting someone in the mental health area of life” with genetic testing. The participants discussed that you are providing someone with a diagnosis associated with high rates of suicide and that this may not be appropriate information for everyone to have. One participant expressed that stigma may be reduced if genetic testing is presented in an environment that allows

individuals to feel that they can still lead a successful life despite their diagnosis. This coincides with requests made by participants in Peay et al. (2009). A small minority of participants in their study asked for psychological support related to illness adjustment, living with personal risk, and family based interventions when giving predictive information.

Additionally, a participant felt that genetic testing should be accompanied by efforts to eliminate stigma in society. Similarly, Jonsson et al. (2011) argues that stigma might be alleviated if there is an increased societal understanding of the experiences of individuals living with mental illness and their family members. The notion that genetic testing may be associated with negative consequences, such as perceived labeling or stigma, is important for genetic counselors to consider when working with individuals and their families. Thus, it is particularly important for genetic counselors to ascertain exactly what BPD means to each individual and family member.

6.2 CONCLUSION

Thematic analysis identified three major themes to consider when working with families with bipolar disorder. Issues revealed through these themes included, concern over delay in diagnosis, effects on relationships in both negative and positive ways and the desire by many for increased education and support from a genetic professional.

Some individuals felt that informing family members of signs and symptoms of bipolar disorder may help expedite a diagnosis of bipolar disorder. The effects on relationships ranged from social distancing, dealing with episodes of anger, increased empathy and a shared connection felt between other family members with mental illness. Reproductive decisions did

not appear to be strongly effected by a diagnosis of bipolar disorder in the family for siblings. As most individuals with bipolar disorder were past reproductive age this study does not have the necessary data to conclude how their own diagnosis of bipolar disorder would impact reproductive decisions. When discussing the potential for a genetic test, a few participants voiced concern over potential consequences, such as increasing stigma. One individual urged that the presentation of genetic information by health care professionals aim to reduce stigma.

Furthermore, this study identified that the majority of individuals would be interested in genetic counseling if it were available to them.

6.2.1 Implications for genetic counseling

As evidenced by this and previous studies, there is interest in genetic counseling for BPD. This study addresses perceptions of individuals with BPD and/or their siblings to consider when working with these families. Genetic counselors are experienced in counseling for many other common, multifactorial disorders, and are able to consider family perceptions in these discussions. Thus, genetic counselors may be a valuable asset to providing additional support to families with BPD.

According to van der Voort et al. (2009) current support for these families is insufficient. Furthermore, research suggests that increased knowledge about what BPD means for family members is needed in order to provide necessary support. Family members have reported feeling that they are not listened to in interactions with healthcare professionals which further exacerbates stress (Ostman and Kjellin, 2005). Genetic counselors are trained to provide support for families. Thus, genetic counselors could serve as an additional source of support for these families and acknowledge that BPD may affect the entire family.

Additionally, genetic counselors are in a position to guide family members toward their own successful coping, as family member are often focused on the individual with BPD and not themselves (Jonsson et al., 2011). Genetic counselors are experienced in providing strategies to family members regarding creating time and space in their own lives to take care of themselves.

6.3 STUDY LIMITATIONS AND FUTURE RESEARCH

As described earlier, snowball sampling was one method used to recruit participants for this study. Despite great potential benefits to snowball recruitment there are limitations to its use. This form of recruitment may be biased, as it is not a random sampling and may not be quite as representative of a larger population (Sadler et al., 2010).

Some participants in this study recruited via snowball sampling were family members. This allowed for greater understanding of the entire family dynamic. A larger study with multiple families is warranted to provide greater representation of families with bipolar disorder. If snowball sampling is used in future larger studies it must be recognized that snowball sampling restricts the researcher from estimating when “saturation” of the sample has been met (Sadler et al., 2010). “Saturation” is reached when no new information is revealed in recruited participants. Due to the potential for shared perceptions among individuals recruited by snowball sampling it is less clear whether new information would be obtained from future participants.

The accessibility of phone interviewing for participants and the researcher allowed for a larger number of participants than conducting in-person interviews. Additionally, some participants experienced fatigue during the interview and thus the interview was reconvened at a later time, which was feasible due to the phone-interview format. This may have been related to

current mood of the participants at the time of the interview. However, there were limitations with communication over the phone. Firstly, some participants had a difficult time understanding some of the vignettes. This led to frequent repetition for some participants, which may have contributed to participants' fatigue. Additionally, comparing the vignettes was problematic for some individuals, as they did not have the first story in front of them to compare. An in-person interview would likely increase the understanding for participants and result in greater clarity of answers for the vignette questions. However, the feeling of anonymity phone interviews can provide would be removed. Mailing the interview guide to study participants ahead of time may be a suitable way to increase the participants' comprehension of the clinical vignettes. Furthermore, future research could utilize mock genetic counseling sessions in lieu of the clinical vignettes. This may allow for more accurate depictions of what participants may answer in an actual genetic counseling session. This would require a researcher adept in advanced genetic counseling skills.

The semi-structured interview format allowed for each participant to discuss what was important to him/her for certain questions. Thus, some themes were elicited because participants happened to discuss the same topic; however, they were not directly questioned on this topic. Thus, perhaps future studies could base questions on the themes identified in this study to assess how broadly these thoughts are represented in individuals with BPD and/or their family members.

Despite potential limitations of phone interviews, most participants were very open to discussing their thoughts and stories. The bond felt between an interviewer and interviewee can be unique. These two individuals must form a trusting relationship quite fast in order to benefit the most from the process. This trust and appreciation may last long after the interview is over.

This was seen in this study when participants called and sent emails to thank the researcher for speaking with them, which was truly moving.

APPENDIX A: IRB APPROVAL LETTERS



University of Pittsburgh Institutional Review Board

3500 Fifth Avenue
Pittsburgh, PA 15213
(412) 383-1480
(412) 383-1508 (fax)
<http://www.irb.pitt.edu>

Memorandum

To: Elizabeth Gettig, MS, CGC
From: Sue Beers, PhD, Vice Chair
Date: 9/23/2009
IRB#: [PRO09070167](#)
Subject: Perceptions of Genetic Counseling from Adults with Bipolar Disorder

The University of Pittsburgh Institutional Review Board reviewed and approved the above referenced study by the expedited review procedure authorized under 45 CFR 46.110 and 21 CFR 56.110. Your research study was approved under:
45 CFR 46.110.(7) characteristics/behaviors

The IRB has determined the risk to be minimal risk.

Please note that the waiver for the requirement to obtain a written informed consent has been approved.

Please note that the advertisement that was submitted for review has been approved as written. As a reminder, any changes to the wording of the approved advertisement would require IRB approval prior to distribution.

Approval Date: 9/23/2009
Expiration Date: 9/22/2010

For studies being conducted in UPMC facilities, no clinical activities can be undertaken by investigators until they have received approval from the UPMC Fiscal Review Office.

Please note that it is the investigator's responsibility to report to the IRB any unanticipated problems involving risks to subjects or others [see 45 CFR 46.103(b)(5) and 21 CFR 56.108(b)]. The IRB Reference Manual (Chapter 3, Section 3.3) describes the reporting requirements for unanticipated problems which include, but are not limited to, adverse events. If you have any questions about this process, please contact the Adverse Events Coordinator at 412-383-1480.

The protocol and consent forms, along with a brief progress report must be resubmitted at least one month prior to the renewal date noted above as required by FWA00006790 (University of Pittsburgh), FWA00006735 (University of Pittsburgh Medical Center), FWA00000600 (Children's Hospital of Pittsburgh), FWA00003567 (Magee-Womens Health Corporation), FWA00003338 (University of Pittsburgh Medical Center Cancer Institute).



University of Pittsburgh
Institutional Review Board

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Memorandum

To: Elizabeth Gettig
From: Sue Beers, PhD, Vice Chair
Date: 9/1/2010
IRB#: [REN10070213](#) / PRO09070167
Subject: Perceptions of Genetic Counseling from Adults with Bipolar Disorder

Your renewal for the above referenced research study has received expedited review and approval from the Institutional Review Board under: 45 CFR 46.110.(7).

Please note the following information:

Approval Date: 8/31/2010
Expiration Date: 8/30/2011

Please note that it is the investigator's responsibility to report to the IRB any unanticipated problems involving risks to subjects or others [see 45 CFR 46.103(b)(5) and 21 CFR 56.108(b)]. The IRB Reference Manual (Chapter 3, Section 3.3) describes the reporting requirements for unanticipated problems which include, but are not limited to, adverse events. If you have any questions about this process, please contact the Adverse Events Coordinator at 412-383-1480.

The protocol and consent forms, along with a brief progress report must be resubmitted at least **one month** prior to the renewal date noted above as required by FWA00006790 (University of Pittsburgh), FWA00006735 (University of Pittsburgh Medical Center), FWA00000600 (Children's Hospital of Pittsburgh), FWA00003567 (Magee-Womens Health Corporation), FWA00003338 (University of Pittsburgh Medical Center Cancer Institute).

Please be advised that your research study may be audited periodically by the University of Pittsburgh Research Conduct and Compliance Office.

APPENDIX B: INTERVIEW GUIDES

Affected Interview - ADULT

This interview includes questions about you and your family and bipolar disorder. You will also be asked to listen to some short stories and to provide your opinion about the information presented. If you have any questions or need anything repeated, please let me know.

1. Please tell me how you were diagnosed with bipolar disorder. When did the symptoms begin?
2. Does bipolar disorder affect your daily life? If so, how?
3. What is the worst thing about bipolar disorder for you? What is the worst thing for your family?
4. What is the best thing about bipolar disorder for you? What is the best thing for your family?
5. How many brothers and sisters do you have?
6. Do you have any children?

If yes- how many? Do you plan to have any more children?

If no- Do you plan to have children in the future?

7. Do you have other family members who have been diagnosed with bipolar disorder? Are there any family members who you think have bipolar disorder or any other mental illness but have not been diagnosed?

For each identified: how the participant is related to them; symptoms/diagnosis

8. What would you say caused your bipolar disorder? Do you think the same event causes bipolar disorder in everyone who is diagnosed?
9. Do you feel that you can control your own symptoms? If so, to what extent are you able to control your own symptoms?
10. To what extent can your family and friends control your symptoms?
11. Has anyone ever treated you differently because you have bipolar disorder? If so, has this affected your willingness to tell others about your diagnosis?
12. Do you feel that bipolar disorder runs in your family? If so, does this concern you?
13. If you were to compare yourself to a person who is similar to you, (same or similar family, same situation growing up, similar friends, etc.) with the exception that the person does not have bipolar disorder, what is the likelihood that this person's children will have bipolar disease?
14. Do you think anything can be done by you or your family members to affect the chance of one of your children developing a mental illness such as bipolar disorder?
15. Would you be interested in learning more about what factors cause bipolar disorder? If so, what type of information would you be interested in?
16. What comes to mind when I say genetics and bipolar disorder?
17. Has your diagnosis of bipolar disorder changed your plans to have children? If so, how? Have any of your family members expressed their opinion? If so, do they share the same opinion as you?

Now I'm going to read you a series of six stories. The stories have a number of different pieces, so if you want me to repeat something, please let me know.

In these stories, Susan/Tom has a brother with bipolar disorder. She/He has questions about the cause of bipolar disorder and is concerned about it happening again in the family. Susan/Tom goes to see a genetic counselor. A genetic counselor is a health care professional who specializes in helping families who have concerns about conditions that can run in the family. After each story I'll ask you to tell me how the information that Susan/Tom learned could be useful or why you think that it is not useful.

1. Susan/Tom goes to a genetic counselor **to learn what causes bipolar disorder**. The genetic counselor tells Susan/Tom that bipolar disorder is caused by a mix of a person's genes and non-genetic things, like the environment that they live in. The genetic counselor explains that there are many genes involved that may be passed down from both sides of the family. Some things in a person's everyday environment, like being exposed to viruses, also may affect the chance of getting bipolar disorder. The genetic counselor says that, while good parenting helps all children's development, parenting style does not cause, or prevent, bipolar disorder. The genetic counselor and Susan/Tom discuss the importance of finding signs of bipolar disorder early and getting treatment right away.

Do you think this information would be useful to Susan/Tom? Why or why not?

2. Susan/Tom goes to the genetic counselor **to learn about the chance that bipolar disorder could happen again** in the family. The genetic counselor takes a careful family history, and asks Susan/Tom questions about the mental health of family members. The genetic counselor also asks about Susan/Tom's own mental health. The genetic counselor uses the family history information to estimate that there is about a 20% chance, which is the same as a 1 in 5 chance, that bipolar disorder could happen again in a young person in Tom's/Susan's family. The genetic counselor says that this chance might not be exactly right, but is probably close. She hopes the information can give Susan/Tom an idea of how likely it is that others in her/his family may get bipolar disorder.

Do you think this information would be useful to Susan/Tom? Why or why not?

The next three stories are about genetic testing. Right now there is no genetic test that can tell someone their chance of getting bipolar disorder, but there may be a test like that in the future. I am going to ask you to think about different kinds of tests that could be available one day.

Each story is a little bit different. If the differences aren't clear, please ask me to say the stories again. In each story, Susan/Tom is interested in genetic testing to learn more about the chance that young people in her/his family will get bipolar disorder.

3. Here is the first story about genetic testing. Susan/Tom goes to a genetic counselor to learn about testing for bipolar disorder. The genetic counselor explains that the test looks for a change in **one gene** that will raise someone's chance of getting bipolar disorder. If the genetic test finds that change in a person's gene, then that person will have a **60% chance, or more than a 1 in 2 chance**, of getting bipolar disorder during their life.

Do you think this information would be useful to Susan/Tom? Why or why not?

4. Now I'm going to tell you a second story about genetic testing. In this one, Susan/Tom goes to the genetic counselor to learn about a **different** genetic test for bipolar disorder. The genetic counselor explains that this test looks at changes in **six different genes**. **Each of these changes** plays a small role in the chance of getting bipolar disorder. If the genetic test shows that a person has changes in all six genes, then that person has a **20% chance**, which is the same as a **1 in 5 chance**, of getting bipolar disorder during their life.

Does this information seem more useful, less useful, or about the same as in the previous story? Why?

5. What if the genetic counselor could give Susan/Tom more information? Say the genetic counselor uses the results from the genetic test **together** with information from Susan/Tom's **family history**. If a person has changes in all six genes and has at least one

family member with bipolar disorder, then that person has a 60% chance, or a more than 1 in 2 chance, of getting bipolar disorder during their life.

Does this information seem more useful, less useful, or about the same as in the previous stories? Why?

Say that we were able to prevent bipolar disorder in people who have a high chance of getting the disease. Would that change the way you thought about any of the stories we just discussed? How?

If you could write the best possible story about how genetics could help Bob/Jan in the future, what would it be? I'll start it and you finish it. "Bob/Jan goes to the genetic counselor, and finds out that..." and you finish it.

That was the last story.

We would like to know:

Would you be interested in attending a genetic counseling session to learn more about risks associated with bipolar disorder?

Can you tell me why you would be interested in a genetic counseling session?

Would you want to learn about risks for yourself and other family members?

What would you expect to happen at such a session?

Now I'll end by asking a few questions about you.

How old are you?

What state do you live in?

What racial or ethnic category do you belong to?

American Indian/Alaska Native

Asian

Native Hawaiian or other Pacific Islander

Black or African American

White

Do you consider yourself to be Hispanic or Latino?

What is your marital status?

Are you presently working, retired, on disability?

This is the end of my questions. Are there other things that you've thought of as we've talked about bipolar disorder and genetics that you'd like to tell me?

Debriefing:

Once tape is off: I'd like you to keep in mind that the stories you heard were made up. Right now there is no genetic testing that can tell risk for bipolar disorder. The chances given to the person in the story for bipolar to happen again in that family are also made up. The chance depends on many things that are specific to each family.

If you are interested in a genetic counseling session, we can assist you with a referral.

Thank you for participating in this study. Do you have any questions or comments for me?

Sibling Survey

This interview includes questions about you and your family and bipolar disorder. You will also be asked to listen to some short stories and to provide your opinion about the information presented. If you have any questions or need anything repeated, please let me know.

First, I am going to ask you questions about your brother or sister, then I'll ask you for your thoughts and experiences.

1. Please tell me how your brother/sister was diagnosed with bipolar disorder. When did the symptoms begin?
2. Do you think bipolar disorder affects your brother/sister's daily life? If so, how?
3. What is the worst thing about bipolar disorder for your brother/sister? What is the worst thing for your family?
4. What is the best thing about bipolar disorder for your brother/sister? What is the best thing for your family?
5. How many brothers and sisters do you have?
6. Do you have any children?

If yes- how many? Do you plan to have any more children?

If no- Do you plan to have children in the future?

7. Do you have other family members who have been diagnosed with bipolar disorder? Are there any family members who you think have bipolar disorder or any other mental illness but have not been diagnosed?

For each identified: how the participant is related to them; symptoms/diagnosis

8. What would you say caused your brother/sister's bipolar disorder? Do you think the same event causes bipolar disorder in everyone who is diagnosed?

9. Do you feel that your brother/sister can control his/her own symptoms? If so, to what extent is he/she able to control his/her own symptoms?

10. Do you feel that you are able to affect your brother/sister's symptoms? If so, to what extent?

11. Has anyone ever treated you differently because you have bipolar disorder in your family? If so, has this affected your willingness to tell others about your brother/sister's diagnosis?

12. Do you feel that bipolar disorder runs in your family? If so, does this concern you?

13. If you were to compare yourself to a person who is similar to you, (same or similar family, same situation growing up, similar friends, etc.) with the exception that the person does not have bipolar disorder (in their family), what is the likelihood that this person's children will have bipolar disease?

14. Do you think anything can be done by you or your family members to affect the chance of one of your children developing a mental illness such as bipolar disorder?

15. Would you be interested in learning more about what factors cause bipolar disorder? If so, what type of information would interest you?

16. What comes to mind when I say genetics and bipolar disorder?

17. Has your brother/sister's diagnosis of bipolar disorder changed your plans to have children? If so, how? Have any of your family members expressed their opinion? If so, do they share the same opinion as you?

Now I'm going to read you a series of six stories. The stories have a number of different pieces, so if you want me to repeat something, please let me know.

In these stories, Susan/Tom has a brother with bipolar disorder. She/He has questions about the cause of bipolar disorder and is concerned about it happening again in the family. Susan/Tom goes to see a genetic counselor. A genetic counselor is a health care professional who specializes in helping families who have concerns about conditions that can run in the family. After each story I'll ask you to tell me how the information that Susan/Tom learned could be useful or why you think that it is not useful.

1. Susan/Tom goes to a genetic counselor **to learn what causes bipolar disorder**. The genetic counselor tells Susan/Tom that bipolar disorder is caused by a mix of a person's genes and non-genetic things, like the environment that they live in. The genetic counselor explains that there are many genes involved that may be passed down from both sides of the family. Some things in a person's everyday environment, like being exposed to viruses, also may affect the chance of getting bipolar disorder. The genetic counselor says that, while good parenting helps all children's development, parenting style does not cause, or prevent, bipolar disorder. The genetic counselor and Susan/Tom discuss the importance of finding signs of bipolar disorder early and getting treatment right away.

Do you think this information would be useful to Susan/Tom? Why or why not?

2. Susan/Tom goes to the genetic counselor **to learn about the chance that bipolar disorder could happen again** in the family. The genetic counselor takes a careful family history, and asks Susan/Tom questions about the mental health of family members. The genetic counselor also asks about Susan/Tom's own mental health. The genetic counselor uses the family history information to estimate that there is about a 20% chance, which is the same as a 1 in 5 chance, that bipolar disorder could happen again in a young person in Tom's/Susan's family. The genetic counselor

says that this chance might not be exactly right, but is probably close. She hopes the information can give Susan/Tom an idea of how likely it is that others in her/his family may get bipolar disorder.

Do you think this information would be useful to Susan/Tom? Why or why not?

The next three stories are about genetic testing. Right now there is no genetic test that can tell someone their chance of getting bipolar disorder, but there may be a test like that in the future. I am going to ask you to think about different kinds of tests that could be available one day.

Each story is a little bit different. If the differences aren't clear, please ask me to say the stories again. In each story, Susan/Tom is interested in genetic testing to learn more about the chance that young people in her/his family will get bipolar disorder.

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Do you think this information would be useful to Susan/Tom? Why or why not?

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Does this information seem more useful, less useful, or about the same as in the previous story? Why?

5. What if the genetic counselor could give Susan/Tom more information? Say the genetic counselor uses the results from the genetic test **together** with information from Susan/Tom's **family history**. If a person has changes in all six genes and has at least one family member with bipolar disorder, then that person has a 60% chance, or a more than 1 in 2 chance, of getting bipolar disorder during their life.

Does this information seem more useful, less useful, or about the same as in the previous story? Why?

Say that we were able to prevent bipolar disorder in people who have a high chance of getting the disease. Would that change the way you thought about any of the stories we just discussed? How?

If you could write the best possible story about how genetics could help Bob/Jan in the future, what would it be? I'll start it and you finish it. "Bob/Jan goes to the genetic counselor, and finds out that..." and you finish it.

That was the last story.

We would like to know:

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Can you tell me why you would be interested in a genetic counseling session?

Would you want to learn about risks for yourself and other family members?

What would you expect to happen at such a session?

Now I'll end by asking a few questions about you.

How old are you?

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Do you consider yourself to be Hispanic or Latino?

What is your marital status?

Are you presently working, retired, on disability?

This is the end of my questions. Are there other things that you've thought of as we've talked about bipolar disorder and genetics that you'd like to tell me?

Debriefing:

Once tape is off: I'd like you to keep in mind that the stories you heard were made up. Right now there is no genetic testing that can tell risk for bipolar disorder. The chances given to the person in the story for bipolar to happen again in that family are also made up. The chance depends on many things that are specific to each family.

If you are interested in a genetic counseling session, we can assist you with a referral.

Thank you for participating in this study. Do you have any questions or comments for me?

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